



## **END OF LIFE CARE BIBLIOGRAPHY November 2004**

1: Acad Med. 2004 Oct;79(10):964-5.

A story that illustrates humanism in medicine: To touch the dying.

Margalit T.

University of Medicine and Dentistry, Robert Wood Johnson Medical School, New Brunswick, NJ, USA.

PMID: 15383355 [PubMed - indexed for MEDLINE]

2: Am J Hosp Palliat Care. 2004 Sep-Oct;21(5):357-64.

Programmatic barriers to providing culturally competent end-of-life care.

Reese DJ, Melton E, Ciaravino K.

School of Social Work, University of Arkansas, Fayetteville, Arkansas, USA.

Despite many efforts to increase access to end-of-life care, culturally diverse groups are still not being served. Interviews of 22 hospice and palliative care program directors in one southeastern state indicated that directors overestimated how well programs are doing in meeting the needs of diverse groups but were very interested in implementing cultural diversity training for their staff. Those who were more concerned about such issues had recruited more diverse volunteers into their programs. The presence of diverse staff or volunteers predicted a more diverse patient population. A number of efforts were underway to develop cultural competence and provide culturally competent care. Several directors reported no efforts in this direction, however. Directors described programmatic barriers and resources needed. The authors concluded that directors should provide leadership in their agencies in welcoming diversity. Implications for further research and work within the larger end-of-life care field are discussed.

PMID: 15510573 [PubMed - in process]

3: America (NY). 2004 Jun 7- Jun 14;190(19):29.

Comment on:

America (NY). 2004 Apr 19-26;190(14):6-13.

At the bedside.

Driscoll DF, Driscoll JJ.

Harvard Medical School, Boston, Mass., USA.

Publication Types:  
Comment  
Letter

PMID: 15459986 [PubMed - indexed for MEDLINE]

4: America (NY). 2004 Apr 19-26;190(14):6-13.

Comment in:  
America (NY). 2004 Jun 7- Jun 14;190(19):29.

Must we preserve life?

Hamel R, Panicola M.

Catholic Health Association, St. Louis, MO, USA.

Publication Types:  
Historical Article

PMID: 15459983 [PubMed - indexed for MEDLINE]

5: Ann Emerg Med. 2004 Jul;44(1):68-70.

"Do not attempt resuscitation" (DNAR) in the out-of-hospital setting.

Schears RM, Marco CA, Iserson KV; ACEP Ethics Committee.

Publication Types:  
Editorial  
Guideline

PMID: 15226711 [PubMed - indexed for MEDLINE]

6: BMJ. 2004 Oct 23;329(7472):939.

Doctors favour legalising assisted suicide for dying patients.

Kmietowicz Z.

Publication Types:  
News

PMID: 15499101 [PubMed - indexed for MEDLINE]

7: BMJ. 2004 Oct 16;329(7471):909-12.

Managing comorbidities in patients at the end of life.

Stevenson J, Abernethy AP, Miller C, Currow DC.

Southern Adelaide Palliative Services, Repatriation General Hospital, 700  
Goodwood Road, Daw Park, South Australia 5041, Australia.

Publication Types:

Review  
Review, Tutorial

PMID: 15485977 [PubMed - indexed for MEDLINE]

8: Br J Nurs. 2004 Sep 9-22;13(16):1003.

The patient should be at the centre of all decisions.

Castledine G.

University of Central England, Birmingham, and Dudley Group of Hospitals NHS  
Trust.

PMID: 15389144 [PubMed - indexed for MEDLINE]

9: Br J Nurs. 2004 Sep 9-22;13(16):984-6.

Not for resuscitation instructions: the law for adult patients in the UK.

Dimond B.

University of Glamorgan.

Case Scenario: Marion, aged 55 years, has suffered from multiple sclerosis for 10 years and had reached the stage where she was wheelchair bound and had become extremely depressed. She was admitted to hospital for review of her medication and treatment plan. She discussed with a nurse what should happen in the event of her suffering a cardiac arrest and stated that she would not wish to be resuscitated. She had not discussed this with her relatives, nor had she put the instructions in writing. Two days later, when her daughter was visiting her, she had a cardiac arrest. Her daughter was anxious every effort should be made to resuscitate her and asked the nurse to call the arrest team. However, the nurse said that Marion had told her that she did not want to be resuscitated and that was therefore binding upon her. The daughter disagreed. What is the law?

Publication Types:

Review  
Review, Tutorial

PMID: 15389142 [PubMed - indexed for MEDLINE]

10: Br J Nurs. 2004 Sep 9-22;13(16):964-8.

Information-seeking behaviour among people with motor neurone disease.

O'Brien MR.

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Lancashire. obrien@edgehill.ac.uk

This qualitative study employed indepth, semistructured audiotaped interviews with seven people with motor neurone disease (MND) to explore their desire for information about MND and their experiences in seeking and obtaining such information. Factors affecting their information-seeking behaviour were identified through a process of interpretative phenomenological analysis. Three distinct information-seeking categories emerged. Active seekers personally acquired information from a variety of sources. Selective seekers had access to information but often relied on 'buffers' to filter out unsuitable material. Information avoiders almost always used a 'buffer' to pre-screen any information to which they were exposed. All participants described negative effects on being exposed to unsolicited information, often in the form of media coverage. This work highlights the impact of unsolicited information on people with MND, an area not previously studied.

PMID: 15389139 [PubMed - indexed for MEDLINE]

11: Br J Nurs. 2004 Aug 12-Sep 8;13(15):895.

Patients do have terminal care rights.

[No authors listed]

Publication Types:  
News

PMID: 15378812 [PubMed - indexed for MEDLINE]

12: Br J Nurs. 2004 Aug 12-Sep 8;13(15):922-4.

Healthcare professionals and euthanasia: current law in the UK.

Dimond B.

University of Glamorgan, UK.

Publication Types:  
Review  
Review, Tutorial

PMID: 15365504 [PubMed - indexed for MEDLINE]

13: Can J Psychiatry. 2004 Jul;49(7):454-7.

Surrogate decision making: special issues in geriatric psychiatry.

Cohen CA.

Department of Psychiatry, University of Toronto, Ontario. carole.cohen@sw.ca

Surrogate decision-makers, usually family and friends, are often called on to assist seniors who are incapable of making certain decisions. The literature to date has focused primarily on decisions regarding medical treatment. Less has been written about issues faced by surrogates when making other types of decisions that often arise in the practice of geriatric psychiatry. This article outlines a case relating to personal care decision-making. The discussion

focuses on areas that need to be addressed to understand and assist surrogates in making personal care decisions in the future.

PMID: 15362249 [PubMed - indexed for MEDLINE]

14: Can Oncol Nurs J. 2004 Spring;14(2):112-6.

Not just any old standards ... 2002 Canadian Hospice Palliative Care Association standards.

[Article in English, French]

West PJ, Ferris F, Balfour H, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A.

Rouge Valley Health System, Scarborough, Ontario.

Publication Types:

Review

Review, Tutorial

PMID: 15230031 [PubMed - indexed for MEDLINE]

15: Cancer Invest. 2004;22(3):466-70.

Philosophical oncology: on being needed--thoughts of a deathwatcher.

Brescia FJ.

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bresciaf@musc.edu

The ultimate bond that connects the patient and the physician requires an understanding of the human drama we call illness. Medical oncology is a specialty filled with the uncomfortable experiences of people facing fear, anxiety, and loss. The caregiver must share in the distress, be troubled by the patient's troubles, but keep a safe distance, so as not to be wounded as well. The physician is not only a deathwatcher for the sickest of patients, but, by necessity, must be self-reflective--a doctorwatcher.

PMID: 15493366 [PubMed - indexed for MEDLINE]

16: CANNT J. 2004 Apr-Jun;14(2):48.

Technologists/Technicians participate in end-of-life care.

Gajaria M.

The Hospital for Sick Children, Toronto, Ontario.

PMID: 15509035 [PubMed - in process]

17: CANNT J. 2004 Apr-Jun;14(2):43-5.

Medication considerations in end-of-life care.

Ledger S.

Publication Types:  
News

PMID: 15509033 [PubMed - in process]

18: Compr Psychiatry. 2004 Jul-Aug;45(4):239-45.

Assessing competence to complete psychiatric advance directives with the competence assessment tool for psychiatric advance directives.

Srebnik D, Appelbaum PS, Russo J.

Department of Psychiatry and Behavioral Sciences, University of Washington, Seattle, 98105, USA.

The Competence Assessment Tool for Psychiatric Advance Directives (CAT-PAD), a new instrument designed to assess competence to complete a psychiatric advance directive (PAD), is described. Initial psychometric properties and data regarding participant performance on the instrument are detailed. Study participants were 80 outpatients with at least two psychiatric crises in the previous 2 years. The CAT-PAD has three scales that assess decisional capacities regarding the nature and value of PADs and a specific treatment choice: Understanding, Appreciation, and Reasoning. Construct and discriminant validity were evaluated using the AD-Maker competence questions, symptom and functioning scales, and clinical and demographic characteristics. Reliability was strong for the Understanding and Reasoning scales and total score, and adequate for the Appreciation scale. Construct validity was demonstrated in relation to the AD-Maker competence questions and scales assessing psychotic symptoms. The CAT-PAD was generally unbiased with respect to gender, ethnicity, and age. Controlling for psychotic symptoms, diagnosis was not significantly related to CAT-PAD scores. Most participants performed well on the CAT-PAD. Using rigid cutoffs for the CAT-PAD is not advised due to lack of consensus on the degree of capacities required for completing a PAD, and differences in situational demands. Routine screening using the CAT-PAD is also not recommended, but rather assessment is suggested when a priori doubts exist about a person's decisional capacity. Such use of the CAT-PAD may allow clinicians to better trust the content of PADs, which may, in turn, increase the likelihood PADs will be honored.

Publication Types:  
Validation Studies

PMID: 15224265 [PubMed - indexed for MEDLINE]

19: Crisis. 2004;25(3):97-8.

End-of-Life decisions in The Netherlands, 1990-2001.

Kerckhof AJ.

Publication Types:  
Editorial

PMID: 15387234 [PubMed - indexed for MEDLINE]

20: Death Stud. 2004 Nov;28(9):829-48.

Affirming the connection: comparative findings on communication issues from hospice patients and hematology survivors.

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The following discussion presents comparative findings from hospice patients and hematology survivors on the topic of talking about dying to significant others within their network of family and friends. The insights have been gathered from an Australian research program that is exploring the notion of spirituality in relation to serious illness. The findings document the participants' awareness, acceptance, and fear of dying. It documents the difficulty associated with talking about dying, which creates voids in relationships and deprives seriously ill individuals of their sense of normality, at a time when they have a strong need to talk and share experiences. Six specific blocks to communication are explored, along with an emphasis on the importance of communicating with others who have a similar life experience.

PMID: 15493077 [PubMed - indexed for MEDLINE]

21: Dermatol Nurs. 2004 Aug;16(4):355-6.

The ultimate advocacy role.

Johnson EM.

Cleveland Clinic Foundation for Advanced Practice Nurses, Cleveland, OH, USA.

For nurses, end-of-life care isn't just about providing compassion. It is also about two very important legal documents.

Publication Types:  
Case Reports

PMID: 15471047 [PubMed - indexed for MEDLINE]

22: Gen Hosp Psychiatry. 2004 Jul-Aug;26(4):323-30.

Psychiatric consultation with regard to requests for euthanasia or physician-assisted suicide.

Groenewoud JH, Van Der Heide A, Tholen AJ, Schudel WJ, Hengeveld MW, Onwuteaka-Philipsen BD, Van Der Maas PJ, Van Der Wal G.

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The objective of this article is to describe the practice of psychiatric consultation with regard to explicit requests for euthanasia or physician-assisted suicide in the Netherlands. Written questionnaires were sent

to an unselected sample of 673 Dutch psychiatrists, about half of all such specialists in the Netherlands. The response rate was 83%. Of the respondents, 36% (199 of 549) had at least once been consulted about a patient's request for physician-assisted death. The annual number of such psychiatric consultations is estimated to be 400 (about 4% of all requests for physician-assisted death). About one in four consultations is initiated by another psychiatrist. Consultants were mainly asked to assess whether the patient had a treatable mental disorder (68%) or whether the patient's request was well considered (66%). Assessment of the influence of transference and countertransference was less frequently sought (24%). Of the 221 consultation cases described, 67 (30%) ended in euthanasia or assisted suicide, whereas another 124 (56%) did not. In most, but not all, cases where the patient's request for physician-assisted death was refused, the respondent had judged that the request was not well considered or that the patient had a treatable mental disorder, or that the decision-making was influenced by transference and countertransference. We conclude that psychiatric consultation for patients requesting physician-assisted death in the Netherlands is rare, as in other countries. The issue of psychiatric consultation with regard to requests for physician-assisted death, especially in patients with a physical disease, needs to be further addressed.

PMID: 15234829 [PubMed - indexed for MEDLINE]

23: Hastings Cent Rep. 2004 Jul-Aug; 34(4):21-31.

Comment in:

Hastings Cent Rep. 2004 Jul-Aug; 34(4):3.

The contribution of demoralization to end of life decisionmaking.

Kissane DW.

Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, USA.

PMID: 15379099 [PubMed - indexed for MEDLINE]

24: Hastings Cent Rep. 2004 Jul-Aug; 34(4):10-1.

Liability for life.

Schneider CE.

University of Michigan, USA.

PMID: 15379093 [PubMed - indexed for MEDLINE]

25: Hastings Cent Rep. 2004 Jul-Aug; 34(4):8-9.

Finding our way.

Weise K.

Cleveland Clinic, USA.

PMID: 15379092 [PubMed - indexed for MEDLINE]



26: Hastings Cent Rep. 2004 Jul-Aug; 34(4):6; author reply 6.

Comment on:

Hastings Cent Rep. 2004 Mar-Apr; 34(2): 30-42.

In defense of living wills.

Carpenter B.

Publication Types:

Comment

Letter

PMID: 15379090 [PubMed - indexed for MEDLINE]

27: Hastings Cent Rep. 2004 Jul-Aug; 34(4):5; author reply 5-6.

Comment on:

Hastings Cent Rep. 2004 Mar-Apr; 34(2): 30-42.

Hastings Cent Rep. 2004 Mar-Apr; 34(2): 9-10.

In defense of living wills.

Carpenter AF.

Publication Types:

Comment

Letter

PMID: 15379089 [PubMed - indexed for MEDLINE]

28: Hastings Cent Rep. 2004 Jul-Aug; 34(4):3.

Comment on:

Hastings Cent Rep. 2004 Jul-Aug; 34(4):21-31.

The other side of the slippery slope.

Ganzini L, Prigerson H.

Oregon Health and Science University, USA.

Publication Types:

Comment

PMID: 15379086 [PubMed - indexed for MEDLINE]

29: Home Healthc Nurse. 2004 Aug; 22(8):576.

Helping patients make their wishes known.

Yetman L.

Housecall Home Health Care, 19321 U. S. Highway 19 N., Clearwater, FL 33764,  
USA. lcyetman@earthlink.net

PMID: 15314567 [PubMed - indexed for MEDLINE]

30: Home Healthc Nurse. 2004 Aug;22(8):566-8.

When patients won't share the prognosis with family.

Turkoski BB.

Kent State University College of Nursing, P.O. Box 240103, Milwaukee, WI 53224,  
USA. bturkoski@kent.edu

PMID: 15314564 [PubMed - indexed for MEDLINE]

31: Int J Palliat Nurs. 2004 Jul;10(7):360; author reply 361-2.

Comment on:

Int J Palliat Nurs. 2004 May;10(5):218-24; discussion 224.

An interview with Lesley Martin.

Joll TA.

Publication Types:

Comment

Letter

PMID: 15378811 [PubMed - indexed for MEDLINE]

32: Int J Palliat Nurs. 2004 Jun;10(6):308-11.

One palliative care nurse's view of euthanasia: a social movement reflective of  
a self-serving generation.

Milliken J.

Ballarat Hospice Care Inc, Ballarat, Victoria 3350, Australia.  
general@ballarathospice.com

Publication Types:

Review

Review, Tutorial

PMID: 15284626 [PubMed - indexed for MEDLINE]

33: Int J Palliat Nurs. 2004 Jun;10(6):270-7.

Decision support: helping patients and families to find a balance at the end of  
life.

Murray MA, Miller T, Fiset V, O'Connor A, Jacobsen MJ.

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Terminally ill patients and their families face many decisions at the end of life that can sometimes be overwhelming. Nurses play a key role in providing decision support so that patients and their families can make timely decisions about their health care that reflect their individual needs and circumstances. The Ottawa Decision Support Framework can help nurses to assess patients' decision-making needs, provide tailored decision support and evaluate the effect of their interventions. The theoretical underpinnings of the model and its implications for palliative care clinical practice are discussed.

Publication Types:

Review  
Review, Tutorial

PMID: 15284621 [PubMed - indexed for MEDLINE]

34: Intensive Crit Care Nurs. 2004 Aug;20(4):214-22.

An insight into Australian nurses' experience of withdrawal/withholding of treatment in the ICU.

Halcomb E, Daly J, Jackson D, Davidson P.

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**BACKGROUND:** The success of biotechnology has created moral and ethical dilemmas concerning end-of-life care in the Intensive Care Unit (ICU). Whilst the competent individual has the right to refuse or embrace treatment, ICU patients are rarely able to exercise this right. Thus, decision-making is left to medical professionals and family/significant others. **AIM:** This study aimed to explore the lived experience of ICU nurses caring for clients having treatment withdrawn or withheld, and increase awareness and understanding of this experience amongst other health professionals. **METHODS:** Van Manens' (1990) phenomenological framework formed the basis of this study as it provided an in-depth insight into the human experience. A convenience sample of ten ICU Nurses participated in the study. Conversations were transcribed verbatim and analysed using a process of thematic analysis. **RESULTS:** Five major themes emerged during the analysis. These were: (1) comfort and care, (2) tension and conflict, (3) do no harm, (4) nurse-family relationships and (5) invisibility of grief and suffering. **CONCLUSION:** The experience of providing care for the adult having treatment withdrawn or withheld in the ICU represents a significant personal and professional struggle. Improvements in communication between health professionals, debriefing and education about the process of withdrawing or withholding treatment would be beneficial to both staff and families and has the potential to improve patient care and reduce burden on nurses.

PMID: 15288875 [PubMed - indexed for MEDLINE]

35: Iowa Med. 2004 Jul-Aug;94(4):24-6.

The changing nature of death--what you need to know about OOH DNRs.

Stephenson L.

Communications and Managing Editor of Iowa Medicine, USA.

PMID: 15457907 [PubMed - indexed for MEDLINE]

36: J Adv Nurs. 2004 Nov;48(4):333-41.

Patient approaches to clinical conversations in the palliative care setting.

Clover A, Browne J, McErlain P, Vandenberg B.

Graduate Student, School of Nursing, Deakin University, Victoria, Australia.

clover a., browne j., mcerlain p. & vandenberg b. (2004) Journal of Advanced Nursing48(4), 333-341 Patient approaches to clinical conversations in the palliative care settingAim. The aim of this paper is to report a study exploring patients' understanding of their discussions about end-of-life care with nurses in a palliative care setting. Background. It is assumed that nurses are central players in patients' major decisions about their care, yet minimal information is available about the complexity of patient-nurse interaction in palliative care, and patients' views of the impact of such interactions on decisions that are made. Method. A modified version of grounded theory was used to collect and analyse interview data collected in 2001-2002 with a convenience sample of 11 patients in a palliative care setting. Interviews focused on each patient's selection of two decisions they had made in the past 6 months that had involved nurses in the decision-making process. Findings. Processes were identified between nurses and patients that facilitated or blocked open discussion and discernment of patients' preferences for care. Six approaches that patients used in their conversations with nurses about their care: wait and see, quiet acceptance, active acceptance, tolerating bossiness, negotiation and being adamant. These approaches are described in terms of how they assisted or impeded autonomous decision-making. Conclusion. Palliative care patients often adopt passive roles and tend not to engage in important decision-making, for various reasons. Professionals need to be made aware of this, and should facilitate an open, trusting relationship with patients in order to ensure that important information passes freely in both directions. Professionals should learn to prioritize patient participation and negotiation in their work. With further research, it should be possible to identify the factors that will allow patients to take a more pro-active role in making decisions about their care, where desired.

PMID: 15500527 [PubMed - in process]

37: J Crit Care. 2004 Jun;19(2):118-9; author reply 119-20.

Comment on:

J Crit Care. 2003 Mar;18(1):17-21.

Distress of clinicians with decisions to withhold or withdraw life-support measures.

Uhlmann AT, Uhlmann DR.

Publication Types:

Comment

Letter

PMID: 15236145 [PubMed - indexed for MEDLINE]

38: J Crit Care. 2004 Jun;19(2):108-17.

A content analysis of forms, guidelines, and other materials documenting end-of-life care in intensive care units.

Clarke EB, Luce JM, Curtis JR, Danis M, Levy M, Nelson J, Solomon MZ; Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup.

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**OBJECTIVE:** The purpose of this study was to determine the extent to which data entry forms, guidelines, and other materials used for documentation in intensive care units (ICUs) attend to 6 key end-of-life care (EOLC) domains: 1) patient and family-centered decision making, 2) communication, 3) continuity of care, 4) emotional and practical support, 5) symptom management and comfort care, and 6) spiritual support. A second purpose was to determine how these materials might be modified to include more EOLC content and used to trigger clinical behaviors that might improve the quality of EOLC. **PARTICIPANTS:** Fifteen adult ICUs—8 medical, 2 surgical, and 4 mixed ICUs from the United States, and 1 mixed ICU in Canada, all affiliated with the Critical Care End-of-Life Peer Workgroup. **METHODS:** Physician-nurse teams in each ICU received detailed checklists to facilitate and standardize collection of requested documentation materials. Content analysis was performed on the collected documents, aimed at characterizing the types of materials in use and the extent to which EOLC content was incorporated. **MEASUREMENTS AND MAIN RESULTS:** The domain of symptom management and comfort care was integrated most consistently on forms and other materials across the 15 ICUs, particularly pain assessment and management. The 5 other EOLC domains of patient and family centered decision-making, communication, emotional and practical support, continuity of care, and spiritual support were not well-represented on documentation. None of the 15 ICUs supplied a comprehensive EOLC policy or EOLC critical pathway that outlined an overall, interdisciplinary, sequenced approach for the care of dying patients and their families. Nursing materials included more cues for attending to EOLC domains and were more consistently preprinted and computerized than materials used by physicians. Computerized forms concerning EOLC were uncommon. Across the 15 ICUs, there were opportunities to make EOLC-related materials more capable of triggering and documenting specific EOLC clinical behaviors. **CONCLUSIONS:** Inclusion of EOLC items on ICU formatted data entry forms and other materials capable of triggering and documenting clinician behaviors is limited, particularly for physicians. Standardized scales, protocols, and guidelines exist for many of the EOLC domains and should be evaluated for possible use in ICUs. Whether such materials can improve EOLC has yet to be determined.

PMID: 15236144 [PubMed - indexed for MEDLINE]

39: J Gen Intern Med. 2004 Oct;19(10):1057-63.

Barriers to Excellent End-of-life Care for Patients with Dementia.

Sachs GA, Shega JW, Cox-Hayley D.

While great strides have been made recently in improving end-of-life care in the United States, people with dementia often die with inadequate pain control, with feeding tubes in place, and without the benefits of hospice care. In this paper, we discuss the most important and persistent challenges to providing excellent end-of-life care for patients with dementia, including dementia not being viewed as a terminal illness; the nature of the course and treatment decisions in

advanced dementia; assessment and management of symptoms; the caregiver experience and bereavement; and health systems issues. We suggest approaches for overcoming these barriers in the domains of education, clinical practice, and public policy. As the population ages, general internists increasingly will be called upon to provide primary care for a growing number of patients dying with dementia. There are great opportunities to improve end-of-life care for this vulnerable and underserved population. J GEN INTERN MED 2004;19:1057 -1063.

PMID: 15482560 [PubMed - in process]

40: J Gerontol Nurs. 2004 Sep;30(9):37-46.

Physician orders for life-sustaining treatment form: honoring end-of-life directives for nursing home residents.

Meyers JL, Moore C, McGrory A, Sparr J, Ahern M.

Intercollegiate College of Nursing, Washington State University College of Nursing, Spokane, Washington 99224-5428, USA.

Physician Orders for Life-Sustaining Treatment (POLST) form provides choices about end-of-life care and gives these choices the power of physician orders. The POLST form assures end-of-life choices can be implemented in all settings, from the home through the health-care continuum. The use of the POLST form was evaluated in a pilot study in nursing homes in two eastern Washington counties. Chart reviews and template analysis of interviews revealed the POLST form accurately conveyed end-of-life wishes in 19 of 21 cases. An informed consent process was evidenced in 16 of 21 cases, and the POLST form was congruent with residents' existing advance directives for health care. The findings support the continued use, development, and evaluation of this promising tool for improving end-of-life care.

Publication Types:  
Multicenter Study

PMID: 15471062 [PubMed - indexed for MEDLINE]

41: J Health Commun. 2004 Jul-Aug;9(4):281-307.

Nationwide newspaper coverage of physician-assisted suicide: a community structure approach.

Pollock JC, Yulis SG.

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Using a community structure approach linking city characteristics and variations in media coverage, the authors examined newspaper coverage of physician-assisted suicide. A nationwide sample of 15 city newspapers yielded 288 articles in a four year period. Content analysis of article "prominence" (placement, headline size, story length, presence of photos) and overall article direction (favorable, unfavorable, or balanced/neutral) yielded a combined and widely varied single score "Media Vector" or measure of issue "projection" for each newspaper. Correlation and factor analysis yielded two significant city characteristic factors: a "stakeholder" factor, age (percent over 75) associated with unfavorable coverage of physician-assisted suicide ( $r = -.491$ ;  $p = .000$ ); and an "access" factor--combining media access (newspaper circulation, cable

stations, FM or AM stations) and health care access (health care facilities, physicians)--linked to favorable coverage ( $r = .472$ ;  $p = .000$ ), combining to account for 46.3 percent of the variance. Western US newspapers and public opinion are most favorable to physician-assisted suicide.

PMID: 15371083 [PubMed - indexed for MEDLINE]

42: J Med Philos. 2004 Apr;29(2):237-52.

Informed consent in Texas: theory and practice.

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The legal basis of informed consent in Texas may on first examination suggest an unqualified affirmation of persons as the source of authority over themselves. This view of individuals in the practice of informed consent tends to present persons outside of any social context in general and outside of their families in particular. The actual functioning of law and medical practice in Texas, however, is far more complex. This study begins with a brief overview of the roots of Texas law and public policy regarding informed consent. This surface account is then contrasted with examples drawn from the actual functioning of Texas law: Texas legislation regarding out-of-hospital do-not-resuscitate (DNR) orders. As a default approach to medical decision-making when patients lose decisional capacity and have failed to appoint a formal proxy or establish their wishes, this law establishes a defeasible presumption in favor of what the law characterizes as "qualified relatives" who can function as decision-makers for those terminal family members who lose decisional capacity. The study shows how, in the face of a general affirmation of the autonomy of individuals as if they were morally and socially isolated agents, space is nevertheless made for families to choose on behalf of their own members. The result is a multi-tier public morality, one affirming individuals as morally authoritative and the other recognizing the decisional standing of families.

Publication Types:  
Historical Article

PMID: 15371190 [PubMed - indexed for MEDLINE]

43: J Med Philos. 2004 Apr;29(2):225-36.

Observations of physician, patient and family perceptions of informed consent in Houston, Texas.

Boisaubin EV.

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Informed consent is one of the most important ethical and legal principles in the United States, including Texas, and reflects a profound respect for individuals and their ability to make decisions in their own best interest. It is also a critical underpinning of medical practice, although how it is actually carried out has not been well studied. A survey was conducted in the private practices and a hospital in the Texas Medical Center in Houston, Texas to ascertain how physicians, patients and patient's family members perceive and

demonstrate the elements of informed consent. In-depth interviews of twelve physicians, three patients and three family members were carried out. For physicians, consent was an explicit and implicit aspect of virtually all medical practice. Physicians would seek patient input concerning medical decisions whenever possible and might also discuss care choices with families. However, they often made decisions based upon what they perceived as the patient's best interests. Patients expected the physician to involve them in the decision process, but whether they turned to family members, or even others to assist them, varied considerably. Although Texas physicians respect the competent patient as the primary decision maker, they may bypass a formal surrogate decision maker to gain input from others, including their own view of what is in the patient's best interest.

PMID: 15371189 [PubMed - indexed for MEDLINE]

44: J Med Philos. 2004 Apr;29(2):207-23.

Strategic ambiguities in the process of consent: role of the family in decisions to forgo life-sustaining treatment for incompetent elderly patients.

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This paper evaluates the Hong Kong approach to consent regarding the forgoing of life-sustaining treatment for incompetent elderly patients. It analyzes the contextualized approach in the Hong Kong process-based, consensus-building model, in contrast to other role-based models which emphasize the establishment of a system of formal laws and a clear locus of decisional authority. Without embracing relativism, the paper argues that the Hong Kong model offers an instructive example of how strategic ambiguities can both make good sense within particular cultural context and serve important moral goals.

PMID: 15371188 [PubMed - indexed for MEDLINE]

45: J Med Philos. 2004 Feb;29(1):61-74.

No safe harbor: the principle of complicity and the practice of voluntary stopping of eating and drinking.

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In recent years, a number of writers have proposed voluntary stopping of eating and drinking as an alternative to physician-assisted suicide. This paper calls attention to and discusses some of the ethical complications that surround the practice of voluntary stopping of eating and drinking. The paper argues that voluntary stopping of eating and drinking raises very difficult ethical questions. These questions center on the moral responsibility of clinicians who care for the terminally ill as well as the nature and limits of the authority they exercise over them.

PMID: 15449813 [PubMed - indexed for MEDLINE]



46: J Pain Symptom Manage. 2004 Nov;28(5):445-50.

Palliative sedation to relieve psycho-existential suffering of terminally ill cancer patients.

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To clarify the prevalence and the characteristics of patients who received palliative sedation therapy for psycho-existential suffering, a questionnaire was sent to 105 responsible physicians at all certified palliative care units in Japan. The participants were requested to report the number of patients who received continuous deep sedation for refractory psycho-existential suffering during the past year, and to provide details of the 2 most recent patients. A total of 81 physicians returned questionnaires (response rate, 80%). Twenty-nine physicians (36%) reported clinical experience in continuous deep sedation for psycho-existential suffering. The overall prevalence of continuous deep sedation was calculated as 1.0% (90 cases/8,661 total patient deaths), and a total of 46 patient histories were collected. Performance status just before sedation was 3 or 4 in 96%, and predicted survival was 3 weeks or less in 94%. The suffering requiring sedation was feeling of meaninglessness/worthlessness (61%), burden on others/dependency/inability to take care of oneself (48%), death anxiety/fear/panic (33%), wish to control the time of death by oneself (24%), and isolation/lack of social support (22%). Before sedation, intermittent sedation and specialized psychiatric, psychological, and/or religious care had been performed in 94% and 59%, respectively; 89% of 26 depressed patients had received antidepressant medications. All competent patients (n=37) expressed explicit requests for sedation, and family consent was obtained in all cases where family members were available (n=45). Palliative sedation for psycho-existential suffering was performed in exceptional cases in specialized palliative care units in Japan. The patient condition was generally very poor, and the suffering was refractory to intermittent sedation and specialized psychiatric, psychological, and/or religious care. Sedation was performed on the basis of patient and family consent. These findings suggest that palliative sedation for psycho-existential suffering could be ethically permissible in exceptional cases if the proportionality and autonomy principle is applied. More discussion about the role of palliative sedation therapy for refractory psycho-existential suffering in end-of-life care is urgently necessary.

PMID: 15504621 [PubMed - in process]

47: J Palliat Care. 2004 Autumn;20(3):193-200.

Living and dying with dignity: reflections on lived experience.

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Considerations of human dignity figure prominently in discussions of health care, and are central in the debate with regard to end-of-life care and the issue of physician-assisted suicide. In this paper I reflect on my experience as a person living with multiple sclerosis in order to explore ways in which prevailing cultural values contribute to the loss of dignity that accompanies incurable illness and disability. I suggest that authentic Christian community may offer an alternative culture with a radically different value system, one that enhances human dignity.

PMID: 15511039 [PubMed - in process]

48: J Palliat Care. 2004 Autumn;20(3):134-42.

Dignity and psychotherapeutic considerations in end-of-life care.

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The basic tenets of palliative care are frequently subsumed under the goal of helping patients to die with dignity. Our research group has studied the issue of dignity, with dying patients serving as the primary informants. This paper reviews some of our findings, including an overview of the Dignity Model that derives from our empirical work. Furthermore, this paper summarizes various psychotherapeutic approaches which have been considered for this vulnerable patient population. Finally, we provide the rationale based on the Dignity Model for a psychotherapeutic intervention we have coined Dignity Therapy. This brief, individualized therapeutic approach has been informed by our dignity work, and specifically designed for application in patients nearing death.

PMID: 15511031 [PubMed - in process]

49: J Support Oncol. 2004 Jan-Feb;2(1):80-7.

Advances in palliative surgery for cancer patients.

Krouse RS.

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Publication Types:

Review

Review, Tutorial

PMID: 15330375 [PubMed - indexed for MEDLINE]

50: JAMA. 2004 Oct 13;292(14):1744.

Comment on:

JAMA. 2004 May 26;291(20):2476-82.

Palliative care for patients with heart failure.

Markowitz AJ, Rabow MW.

Publication Types:

Comment

PMID: 15479940 [PubMed - indexed for MEDLINE]

51: JAMA. 2004 Oct 13;292(14):1738-43.

Decision making at a time of crisis near the end of life.

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As patients approach the end of life, their disease process may create an immediate life-threatening emergency, yet invasive interventions may be less likely to provide benefit while carrying the same or greater risks. Knowing when it is time to shift from life-prolonging to more palliative approaches, focused on quality of life and comfort, is emotionally and clinically challenging for patients, families, and physicians. Key factors in the decision process include prognosis, risk-benefit analysis of the proposed intervention, current symptom burden, temporal pattern of the illness, patient's age and life stage, and the patient's goals of care. A structured approach to decision making includes assessing the patient's physical, psychological, and spiritual needs; assessing the patient's support system; discussing prognosis; and assessing patient-specific goals. Physicians can best help patients decide which treatments are appropriate by taking the necessary time to explore all curative and palliative care options, providing honest and timely prognostic information, making clear recommendations, facilitating patient-family discussions, and affirming patient choices.

Publication Types:

Case Reports

PMID: 15479939 [PubMed - indexed for MEDLINE]

52: Med Health Care Philos. 2004; 7(2): 209-15.

Mental competence and surrogate decision-making towards the end of life.

Stratling M, Scharf VE, Schmucker P.

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German legislation demands that decisions about the treatment of mentally incompetent patients require an 'informed consent'. If this was not given by the patient him-/herself before he/she became incompetent, it has to be sought by the physician from a guardian, who has to be formally legitimized before. Additionally this surrogate has to seek the permission of a Court of Guardianship (Vormundschaftsgericht), if he/she intends to consent to interventions, which pose significant risks to the health or the life of the person under his/her care. This includes 'end-of-life decisions'. Deviations from this procedure are only allowed in acute emergencies or cases of 'medical futility'. On the basis of epidemiological and demographical data it can be shown that the vast majority of surrogate decisions on incompetent patients in Germany is not covered by legally valid consent. Moreover, the data suggests that if consent were to be requested according to the legal regulations, both the legal and medical system could realistically never cope with the practical consequences of this. Additionally, empiric research has revealed serious deficits concerning medical 'end of life-decisions' and practical performance in palliative care. As a consequence a multidisciplinary discussion has developed in Germany about the reform of present legislation with respect to key-issues like the assessment of mental competence, the options for exercising patient self-determination via advance directives and durable powers of attorney, the improvement of palliative care facilities, the clarification of formal

procedures for surrogate decision-making in health care and towards the end of life and the possibilities and their limitations of controlling these decision-making processes 'externally' (e.g., by Guardianship Courts or committees). The authors discuss those proposals, which clearly dominate the present debate: They all aim to comply with the scientific basis of German law, jurisdiction and the European traditions of philosophy of health care and bioethics.

PMID: 15379196 [PubMed - indexed for MEDLINE]

53: Medsurg Nurs. 2004 Aug;13(4):261-4.

Comment in:

Medsurg Nurs. 2004 Aug;13(4):210, 225.

Assisted suicide and nursing ethics.

Mathes MM.

Center for Advocacy for the Rights and Interests of the Elderly, Philadelphia, PA, USA.

PMID: 15384480 [PubMed - indexed for MEDLINE]

54: Minn Med. 2004 Jun;87(6):50-2.

A perspective on homelessness, ethics, and medical care.

Ratner E, Bartels D, Song J.

Center for Bioethics, University of Minnesota, USA.

People who are homeless are known to have high rates of morbidity and mortality. Yet their attitudes, values, and desires regarding end-of-life care have not been studied. This article reports on the findings from interviews with groups of homeless individuals in the Twin Cities performed by University of Minnesota researchers. It explores the implications of homelessness on two commonly discussed ethical principles-autonomy and justice.

PMID: 15287625 [PubMed - indexed for MEDLINE]

55: Minn Med. 2004 Jun;87(6):30-1.

Daily decisions. Even as new biotechnologies expand the horizons of bioethics, focus needs to be placed on the ethics of everyday practice.

Gessert CE.

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PMID: 15287620 [PubMed - indexed for MEDLINE]

56: Minn Med. 2004 Jun;87(6):4.

Ambiguous choices.

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Publication Types:  
Editorial

PMID: 15287614 [PubMed - indexed for MEDLINE]

57: Monaldi Arch Chest Dis. 2004 Jan-Mar;61(1):50-7.

Ethics, attitude and practice in end-of-life care decision: an European perspective.

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Only in the last decade in Europe has there been increased attention dedicated to the end-of-life care in the hospital, especially in the Intensive Care Unit (ICU). The definitions of the potential decision are extremely important. Withholding is a planned decision not to institute therapies that were otherwise warranted, Withdrawal is the discontinuation of treatments that had been started, Terminal sedation consists of pain and symptom treatment with the possible side effect of shortening life, while Euthanasia means that a doctor is intentionally killing a person who is suffering unbearably and hopelessly at the latter's explicit informed request. The overall incidence of these practices in Europe is only partially known, but there are important differences between Countries or regions, reflecting the absence of a common strategy even within the European Community. Only <15% of ICU patients retain decision making capacity, allowing the impossibility of discussing the decision with them. It is rare that the patient's family is involved in the decision and when such case does arise, the relatives rate the communication with hospital staff poor. The "shared decision" taken together by physicians, nurses, and the patient's family may be the best approach for end-of-life decision, therefore common European guidelines are needed.

PMID: 15366337 [PubMed - indexed for MEDLINE]

58: N C Med J. 2004 Jul-Aug;65(4):242-5.

Guiding the decisions of physicians and families in end-of-life care: the case of long-term feeding tube placement.

[No authors listed]

PMID: 15481496 [PubMed - in process]

59: N C Med J. 2004 Jul-Aug;65(4):229-35.

Opioids in end-of-life care: promises and problems.

Stephenson RC.

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PMID: 15481493 [PubMed - in process]

60: N C Med J. 2004 Jul-Aug;65(4):209-12.

Hospice: a vital service facing increasing demands.

Person JL.

Division of Quality End-of-Life Care, National Hospice and Palliative Care  
Organization, USA. jlundperson@nhpco.org

PMID: 15481488 [PubMed - in process]

61: Natl Cathol Bioeth Q. 2004 Autumn;4(3):579-81.

Considerations on the scientific and ethical problems related to the vegetative  
state.

World Federation of Catholic Medical Associations; Pontifical Academy for Life.

PMID: 15452935 [PubMed - indexed for MEDLINE]

62: Natl Cathol Bioeth Q. 2004 Autumn;4(3):573-6.

On life-sustaining treatments and the vegetative state: scientific advances and  
ethical dilemmas.

Pope John Paul II.

Publication Types:  
Addresses

PMID: 15452934 [PubMed - indexed for MEDLINE]

63: Natl Cathol Bioeth Q. 2004 Summer;4(2):367-70.

On life-sustaining treatments and the vegetative state--scientific advances and  
ethical dilemmas.

John Paul II P.

PMID: 15281185 [PubMed - indexed for MEDLINE]

64: Neurology. 2004 May 25;62(10):1766-70.

Disparities in perceptions of distress and burden in ALS patients and family  
caregivers.

Adelman EE, Albert SM, Rabkin JG, Del Bene ML, Tider T, O'Sullivan I.

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**OBJECTIVES:** To examine agreement between end-stage ALS patients and their family caregivers on indicators of physical and psychological status at the end of life. **METHODS:** Patient-caregiver pairs completed monthly interviews in patient homes. Patients were asked to rate their current pain, energy, suffering, depression, control over ALS, optimism, interest in hastened death, weariness from ALS, will to live, and how burdened they thought caregivers were on Visual Analogue Scales. Caregivers completed identical ratings of patients as well as a measure of their own burden. Both independently completed the ALS Functional Rating Scale-Rev. (ALSFRS-R), a measure of patient disability and physical function. **RESULTS:** A total of 69 patient-caregiver pairs participated. For measures of physical function, kappa ranged from 0.49 to 0.83, indicating moderate to excellent agreement. Patient and caregiver composite ALSFRS-R scores were highly correlated ( $r = 0.92$ ,  $p < 0.001$ ). Agreement between patients and caregivers was high for ratings of patient pain, control over ALS, optimism, and will to live, and this level of agreement remained high over multiple assessments. In pairwise analyses, caregivers rated patients as having less energy, greater suffering, and greater weariness than patients indicated for themselves, whereas patients rated caregivers as more burdened than caregivers reported for themselves. **CONCLUSIONS:** Caregivers can accurately report information about a patient's physical function at the end of life. However, patients and caregivers each overestimated the psychosocial impact of the disease on the other.

PMID: 15159475 [PubMed - indexed for MEDLINE]

65: Nurs Ethics. 2004 Sep;11(5):500-13.

Truth-telling in clinical practice and the arguments for and against: a review of the literature.

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In general, most, but not necessarily all, patients want truthfulness about their health. Available evidence indicates that truth-telling practices and preferences are, to an extent, a cultural artefact. It is the case that practices among nurses and doctors have moved towards more honest and truthful disclosure to their patients. It is interesting that arguments both for and against truth-telling are established in terms of autonomy and physical and psychological harm. In the literature reviewed here, there is also the view that truth-telling is essential because it is an intrinsic good, while it is argued against on the grounds of the uncertainty principle. Based on this review, it is recommended that practitioners ought to ask patients and patients' families what informational requirements are preferred, and research should continue into truth-telling in clinical practice, particularly to discover its very nature as a cultural artefact, and the other conditions and contexts in which truth-telling may not be preferred.

Publication Types:

Review

Review, Tutorial

PMID: 15362359 [PubMed - indexed for MEDLINE]

66: Nurs Stand. 2004 Aug 25-31;18(50):18.

Assisted dying.

Buchanan M.

PMID: 15384302 [PubMed - indexed for MEDLINE]

67: Nursing. 2004 Sep;34(9):71.

A different kind of shower.

Fogle P.

Hospice of Washington County, Hagerstown, Md., USA.

PMID: 15345956 [PubMed - indexed for MEDLINE]

68: Palliat Med. 2004 Jul;18(5):482-3.

Dying and defibrillation: a shocking experience.

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Palliative Care physicians are frequently involved in the care of patients with significant comorbidity and often have to take coexisting conditions into account when treating patients. An example of an area in which this is particularly relevant and will undoubtedly increase is presented with the case report of a patient with terminal metastatic lung carcinoma and an Implantable Cardioverter Defibrillator (ICD) in place. The role of the ICD in preventing the patient from dying comfortably is discussed, as are means of deactivating the device. We conclude that patients with ICDs and terminal disease should have the issue of deactivation addressed at the earliest possible opportunity as practical difficulties may arise in the emergency setting, especially in the nonhospital environment.

Publication Types:

Case Reports

PMID: 15332427 [PubMed - indexed for MEDLINE]

69: Palliat Med. 2004 Jul;18(5):468-77.

The end of life: informal care for dying older people and its relationship to place of death.

Visser G, Klinkenberg M, Broese van Groenou MI, Willems DL, Knipscheer CP, Deeg DJ.

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**OBJECTIVE:** This study examined the features of informal end-of-life care of older people living in the community and the association between informal care characteristics and dying at home. **METHODS:** Retrospective data were obtained from interviews and self-administered questionnaires of 56 persons who had been primary caregivers of older relatives in the last three months of their lives. **RESULTS:** Results showed that informal caregivers of terminally ill older people living in the community provided a considerable amount of personal, household, and management care. Secondary informal caregivers and formal caregivers assisted resident primary caregivers less often than nonresident primary caregivers. Primary caregivers who felt less burdened, who gave personal care more intensively, and/or who were assisted by secondary caregivers, were more likely to provide informal end-of-life care at home until the time of death. **CONCLUSIONS:** Our study showed that informal care at the end of life of older people living in the community is complex, since the care required is considerable and highly varied, and involves assistance from secondary informal caregivers, formal home caregivers as well as institutional care. Burden of informal care is one of the most important factors associated with home death. More attention is needed to help ease the burden on informal caregivers, specifically with regard to resident caregivers and spouses. Since these resident caregivers were disadvantaged in several respects (i.e., health, income, assistance from other carers) compared to nonresident caregivers, interventions by formal caregivers should also be directed towards these persons, enabling them to bear the burden of end-of-life care.

PMID: 15332425 [PubMed - indexed for MEDLINE]

70: Palliat Med. 2004 Jul; 18(5):460-7.

Older people's views about home as a place of care at the end of life.

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**OBJECTIVES:** To explore the attitudes of older people towards home as a place of care when dying. **DESIGN:** A two-phase qualitative study using focus groups and semi-structured interviews. **PARTICIPANTS:** Eight focus group discussions were held with 32 participants recruited from six purposively selected community groups representing older people in Sheffield, UK. A further 16 men and 29 women participated in semi-structured interviews. **RESULTS:** Participants identified that home was more than a physical location, representing familiarity, comfort and the presence of loved ones. While participants anticipated that home would be their ideal place of care during dying, practical and moral problems associated with it were recognised by many. Some had no informal carer. Others did not want to be a 'burden' to family and friends, or were worried about these witnessing their suffering. Those who had children did not wish them to deliver care that was unduly intimate. Concerns were expressed about the quality of care that could be delivered at home, particularly in relation to accommodating health technologies and providing adequate symptom relief. Worries were also expressed about those living in poor material circumstances. Mixed views were expressed about the presence of professional carers within the home. Although they were seen to provide much needed support for the informal carer, the presence of 'strangers' was regarded by some as intrusive and compromising the ideal of 'home'. **DISCUSSION:** Older people perceive factors they associate with 'home' as crucial to a good death, most notably presence of friends and family, but many anticipate that they would prefer to be cared for elsewhere when dying. These findings run counter to assumptions that the medicalised, institutional death cannot be a 'good death'. It is important that dying in hospital is not

demonized, but rather efforts made to examine how institutional deaths can take on a more meaningful quality.

PMID: 15332424 [PubMed - indexed for MEDLINE]

71: Palliat Med. 2004 Jul;18(5):404-8.

Is there such a thing as a good death?

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The idea of a 'good death' is one which has been central to the palliative care movement but which in fact predates it. A number of recent articles have grappled with the concept. It is a subject which is difficult to quantify scientifically and this article explores the territory using a number of philosophical, theological, historical and literary sources. The changing meaning of the concept is traced through the premodern, modern and postmodern periods. In particular the influence on Western ideals about death of the two paradigmatic stories of the deaths of Socrates and Jesus are examined. It is argued that the dualistic thinking of Plato, which often underlies our thinking about death, is no longer adequate and the author offers the thinking of the Spanish philosopher Miguel de Unamuno as an alternative way of approaching our attitudes to death. Although the article does not seek to give a definitive answer to the question it raises, it suggests that thinking about good death should be broadened to accept the struggle with which many people face their death.

PMID: 15332418 [PubMed - indexed for MEDLINE]

72: Psychiatr Serv. 2004 Jul;55(7):751-2, 763.

Comment in:

Psychiatr Serv. 2004 Sep;55(9):1067; author reply 1067-8.

Law & psychiatry: psychiatric advance directives and the treatment of committed patients.

Appelbaum PS.

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PMID: 15232012 [PubMed - indexed for MEDLINE]

73: S D J Med. 2004 Aug;57(8):295-7.

Comfort One: introducing South Dakota's CPR program.

Harris MH.

Publication Types:  
Editorial

PMID: 15379149 [PubMed - indexed for MEDLINE]

74: S D J Med. 2004 Jul;57(7):253-4.

CPR--making sensible end-of-life choices.

Harris MH.

Publication Types:  
Editorial

PMID: 15332317 [PubMed - indexed for MEDLINE]

75: Soc Psychiatry Psychiatr Epidemiol. 2004 Aug;39(8):673-80.

Models of advance directives in mental health care: stakeholder views.

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**OBJECTIVE:** The aim of this study was to examine perceptions of the place of advance directives in mental health care. **METHODS:** Postal survey of stakeholders was carried out to assess their views on different models of advance directives in mental health care. A total of 473 responded. **RESULTS:** In all, 28% of psychiatrists thought advance directives were needed compared to 89% of voluntary organisations and above two-thirds of the other stakeholder groups. There were clear tensions between patient "autonomy" and "right to treatment" which underpin many of the concerns raised. Autonomy provided by advance directive can be contrasted with a co-operative partnership approach to advance planning. The legal status of advance directives is important for some people in relation to treatment refusal. There was general concern about the practical issues surrounding their implementation. **CONCLUSION:** There is a wide range of views in all stakeholder groups about the possible form advance directives should take. Although there is a widespread desire to increase patient involvement in treatment decisions, which advance directives could possibly help to realise, they may also have unwanted consequences for mental health services and individuals.

PMID: 15300379 [PubMed - indexed for MEDLINE]

76: Urol Nurs. 2004 Aug;24(4):270-4, 279; quiz 280.

Being there: the essence of end-of-life nursing care.

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Competent and compassionate end-of-life care is the right of everyone. Nursing and the health care profession are obligated to meet this need for their patients and provide crucial information and support. Continued efforts must be made to increase our knowledge about the normal dying process, symptom management, and the role of the interdisciplinary team in supporting patients in

their final wishes for a "good death".

Publication Types:  
Case Reports

PMID: 15446377 [PubMed - indexed for MEDLINE]